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Introduction

The project, "Identifying and Reaching Populations at Risk: the Paradox of Breast Cancer Control," aimed to examine the shifting demographics of the medically underserved and identify sociocultural factors that might be acting as new or previously unobserved barriers to care. Specifically, we focused on informing a multidimensional model of underservedness as it pertains to secondary breast cancer prevention: the use of screening mammography and clinical breast exams. This expanded model of underservedness is to form the foundation of a research and clinical program to extend appropriate and culturally/socially sensitive breast cancer screening to the underserved. We used a qualitative, semi-structured interview methodology to document not only what are the shifting social, cultural and logistical barriers to care; but also to gain insight into the underlying logic supporting these barriers and how this logic (and hence these barriers) is perpetuated. Results of this project will serve as a basis for identifying and understanding broad, cross-cultural barriers to breast cancer screening, as well as providing insight into culturally- and socially-specific barriers to breast cancer screening. The guiding assumption of this work is that understanding the shifting demographics of medical underservedness for breast cancer and identifying and making recommendations for removal of barriers across populations will improve patient compliance in breast cancer screening. Additionally, we hypothesize that understanding culturally- and socially-specific barriers to breast cancer screening is the first step toward developing practical guidelines for culturally-competent breast cancer prevention, making it possible for health care practitioners to work in partnership with patients who would benefit from increased screening efforts, as well as other new technologies that offer the promise of finding breast cancers in their earliest, most treatable stages.

Body

Task 1: Focus group discussions

In order to guide the development of the data gathering guide used by interviewers to collect qualitative data for this study, we conducted a series of focus groups among women aged 40 and over (women eligible for annual mammography). Discussion was guided toward barriers to access and perceptions of mammography. In addition to providing insight into these issues, focus group participants also guided us in understanding how issues of fear of cancer, distrust of the health care system, and gender-based distrust of male physicians and technicians plays a role in non-compliance with mammography recommendations.

We conducted two focus groups as part of this step. Participants were recruited through advertisements placed in local newspapers. Ten participants were scheduled for one of two five-person groups on the basis of participant availability; four participants attended the first group and five participants attended the second group. Average age for the first group was 63.8, and average age for the second group was 58.8. The first group consisted of two African American women and two Caucasian women, and the second group consisted of four African American women and one Caucasian woman. Both focus groups were led by the same members of the research team, and both sessions were audiotaped, transcribed, and analyzed for similarities in content.

Task 2: Development of Survey Instruments

In addition to the information gathered in Task 1, numerous steps were taken to collect information for developing the survey instruments for this study.

We gathered information from an extensive literature review of existing studies of decision making in breast cancer screening, barriers to preventive care versus barriers to acute care, cultural and social barriers to breast cancer screening, language barriers, reasons for eschewal of preventive and cancer screening care, explanatory models of illness, the problems of special populations at risk such as lesbians, and decision making factors for patients with other types of cancer.

We conducted numerous discussions with several community leaders of the African American, Latino, Chinese (Mandarin- and Cantonese-speaking) and Lesbian/Bi communities. These individuals interact with and encourage women in their community groups to encourage screening and public health awareness in several areas: cancer, AIDS, preventive care visits and pre and post natal care, among them. Therefore, they were able to provide us with much insight into how cancer screening recommendations are accepted and accessed, what barriers exist that prevent access, who among their communities are underserved, and what other factors aside from access barriers contribute to that underservedness. These individuals were also invaluable in providing information on tailoring our work to be culturally and socially sensitive to each different population.

With this information, we developed a pilot demographic survey, a pilot free-listing survey and a pilot data gathering guide for conducting semi-structured interviews (Appendix A). After the research team and community contacts critically reviewed these documents, they were revised and administered to a pilot sample group of five African

American and Caucasian women at the University of Pennsylvania. Because of the possibility that some of the women we interview might be illiterate or have sight problems, we made the decision to administer all three data gathering steps through the interviewer reading them aloud and recording responses. The purpose of this pilot step was to ensure that all three data-gathering documents were laid out correctly; did not carry conceptual or logical errors; did not carry sequential errors; were adequately culturally-sensitive; that the interviewers were asking questions reliably, collecting appropriate fieldnotes and practicing low-bias data gathering techniques; that the data gathering process was not too long but was sufficiently sensitive to elicit in-depth information; were able to be understood readily in an oral format, and that respondents were not offended by or did not misconstrue questions in any way. At the end of each of the pilot interviews, interviewers asked respondents to provide comments and critique the interview process.

All interviews were transcribed, coded and analyzed for content. Interviewers appraised their performances. After several meetings to review of the results of this pilot step, we made the decision to ask more general questions in the semi-structured data gathering step. The rationale for this decision was the unanimous concern that the questions as asked in the pilot survey were highly specific and might bias the respondents toward a single response. Further, we decided to consolidate free-listing questions in order to understand how respondents constructed their concepts of pre-specified categories such as preventive care, acute care, health maintenance, barriers to preventive care, barriers to sick care, barriers to mammography, and preventive medicine. Although it is important to allow respondents to guide the research team in understanding what cognitive domains are important to screening and what factors or elements make up those cognitive domains, we were more concerned with shifts in barriers and underservedness. Therefore, instead of encouraging respondents to build a complete picture of screening behaviors from the "ground up," we decided to ask about cognitive domains that are important to breast cancer screening and care, and to investigate divergences between respondents' experienced barriers and their models of appropriate breast cancer screening behavior and the barriers and models currently held to be important by the health care community. This consolidation and guided interview step had the added benefit of reducing the total interview time by an average of 15 minutes. Finally, we made the decision to add questions regarding uptake and willingness to utilize new cancer prophylactic technologies such as chemoprevention (tamoxifen, raloxifene) and genetic testing for BRCA1 and BRCA2 mutations. These questions were added in order to ensure that future work might focus on applying the understanding of current barriers to breast cancer screening to future uptake and utilization of new preventive technologies, allowing researchers to address and reduce potential barriers to breast cancer prevention before these potential barriers increase cancer burden and result in loss of life.

Respondent comments were taken into account, resulting in wording changes; changes to the income levels in the demographic portion of the interview; and splitting single larger scenario-based questions into two or more smaller, logically dependent and progressive questions. Additionally, respondent requests for information regarding Breast Self Exams (BSE) were taken into account, and we thereafter provided each respondent with culturally- and socially-sensitive information regarding mammograms, breast cancer etiology, BSE, and phone numbers of hospitals and radiology clinics throughout the city that provide free mammograms.

We consolidated all of the information we gathered in the steps described above to write three final data gathering guides: a demographic survey, a free-listing (cognitive domain construction) exercise and a data gathering guide for semi-structured interviews. These documents were used in data gathering (Appendix B, C, and D).

Task 3: Research Conducted to Date

Identification and recruitment of subjects

The paradox of breast cancer control lies in the fact that women who do not access medical care at all (those who are most underserved) are the most difficult to reach. They may not have medical records, they may switch clinics and physicians after each visit, they may lack telephones or steady addresses, and are consequently unable to be accessed through traditional random sampling methods. Paradoxically, those women who are most underserved never are represented by data explaining underservedness. Therefore, as we attempted to inform a larger model of underservedness, we also attempted to include women in this truly underserved category in our study. In order to capture this segment of society, we recruited respondents through a referral tree or snowball sampling method. Snowball sampling has been shown to be effective in reaching hidden populations where the focus of the study is on a behavior that is hard to observe, or one where its practice would exclude individuals from view of researchers. In the context of normal random sampling methods, women who eschew medical care or who have never seen a physician for want of insurance, would constitute a hidden population, difficult to access by a random sample of addresses, medical records, clinic records, Medicare/Medicaid records or census data. Study respondents who fit the selection criteria of a study and who practice the behavior that might exclude them from probability samples (non-ownership of a phone, eschewal of medical care) provide referrals to other people who also may fit the selection criteria. While snowball sampling often generates "false" referrals of people who actually do not fit study criteria, careful screening of each referral for adherence to the study criteria has ensured an appropriate sample. Testing these sampling methods in the contexts of social epidemiological studies is an important step towards developing rigorous and informed studies of excess cancer burden among the underserved. In order to manage the referral chains effectively, we created and followed a protocol based on five steps outlined by Biernacki & Waldorf [1] (Appendix E). We initiated seven different trees: Middle-Class and Working-Class African American, Middle-Class and Working-Class Caucasian, Mandarin- and Cantonese-speaking Chinese, Lesbian/Bi, Women with other chronic disease, Puerto-Rican Latina, and Homeless women. Although seven different trees were initiated, only three referral trees (Middle-Class and Working-Class African American, Women with other chronic disease, and Homeless women) yielded consistent and appropriate referrals (mainly through women of African American ethnicity). Two trees were terminated for consistently referring male and otherwise ineligible respondents (Middle-Class and Working-Class Caucasian, Puerto-Rican Latina) one tree returned only one referral (Cantonese-speaking Chinese) and one never returned any referrals (Lesbian/Bi) despite consistent follow-up from all referral tree initiators. This referral tree method was further complicated by several changes in leadership among the community groups we used as platforms for initiating referral trees and contacting respondents in the event these respondents did not have telephones, did not speak English, or were homeless. These changes in leadership resulted in recruitment criteria being misunderstood or mis-communicated over time and across new employees, loss of follow-up with new community leaders, decisions by new community leaders to discontinue work with our research team, and miscommunication of time

and place to participate in community activities, such as the Lesbian/Bi community annual health day and softball matches (where participation would have increased our acceptability and trust within that community). We used Saturation Method to judge appropriate sample size, continuing to enroll respondents from a specific tree and/or ethnic group until no new themes emerged in their responses. As of July, 2002, we had interviewed 24 women. Originally, we had intended to conduct semi-structured interviews with 40 women. In order to improve recruitment rates, the DoD granted a one-year, no-cost extension. Over the course of 2003, we conducted semi-structured interviews with an additional five women, yielding a total of 29 interviews. In accordance with the methodology of saturation sampling, we terminated accrual when additional interviews consistently yielded no new data.

All respondents were compensated \$20 for their time. Respondents were given the study inclusion criteria and asked to refer friends, family and acquaintances that might be eligible. Additionally, some respondents posted our flyers instead of giving them out to friends and family. This resulted in the start of two additional referral trees, which have started to recruit potential respondents as of July, 2002.

Development of data management system

The need to maintain complete confidentiality and anonymity of respondents; in keeping with DoD and University of Pennsylvania IRB requirements to protect respondent privacy; along with the need to track referrals and maintain respondent name, address and phone numbers in order to facilitate interview rescheduling and sharing an individual's research data with her if she so requested; necessitated the development of a unique data management system.

First, a tracking database was established to record not only respondent name, address, phone number, and time and location of interview, but also to track which referral tree each respondent was referred from, and the unique identifiers of those individuals she referred. This information was kept in a password-protected MS Access file on a locked, password-protected computer in the project manager's office. This file was by nature and application entirely separate from the qualitative and quantitative data software packages used to store and analyze interview and free-listing data.

Each respondent was assigned a unique identity code to separate her raw data from all other respondents' data. This code stood in lieu of personally identifiable information within the raw data databases; at no time were names, birthdates, addresses, phone numbers, or any other potentially personally identifying information stored with data from this project. Names and phone numbers were taken solely for purposes of rescheduling if the need arose and were stored in the respondent tracking database. Unique identifying codes were NOT linked to personally identifying information in the tracking data-base. In order to identify personal data with interview transcripts, respondents would be asked to give their birthdates and answer one other question from the demographic survey, which would then be used to initiate a quick search of the transcribed interviews and identify which interview transcript was the respondent's. To date only one individual has requested a transcript of her interview; this was mailed to her promptly.

System backups were done on a weekly basis. Hard copies of all coding dictionaries and the content-analysis dictionary are maintained and stored by the project manager and the research coordinator. Raw data such as audiotapes, demographic data, coded texts; consent forms; and any other sensitive or research-related physical files are kept in a

locked filing cabinet on a locked floor in our research facility which itself is locked and accessible only to authorized staff. Only members of the research team and the University of Pennsylvania IRB Human Subjects Committee (in accordance with University IRB requirements for research involving human subjects) and the grantor (the Department of Defense) have access to this raw data.

All potential respondents called the project manager on a special, toll-free line used specifically for research purposes. Either the project manager or a research assistant screened each potential respondent for eligibility at the time of the call and scheduled interviews with eligible respondents at a later time. One of three trained interviewers was assigned to conduct the interview. All interviewers were female, and when possible, an attempt was made to match the ethnicity and age of the interviewer with the ethnicity and age of the respondent.

Obtaining Consent

Interviewers read consent forms aloud and audiotaped consent in order to accommodate illiterate and visually-impaired respondents. Respondents were given a copy of the consent form for their own review. In the event respondents did not wish to be audiotaped, interviewers were prepared to take notes. Only one respondent declined audiotaping and preferred to conduct the interview over the telephone. We mailed a consent form to her and she returned it, unsigned but written upon. To date she has not returned the second form we mailed her, and consequently, we will not include her data in our analyses until we obtain signed or audiotaped consent from her to do so.

Data Gathering

For all other respondents, audiotaped free listing exercises and semi-structured interviews were conducted using a data-gathering guide consisting of domain-oriented questions followed by specific probes. Questions and probes were designed to elicit respondents' EMs of breast cancer development and their opinions about the structure of the health care system. However, questions were purposely kept very general to encourage discussion on a broad range of topics and views. Probes consisted of requests to explain or clarify terms, points and concepts unfamiliar to the interviewer. At the end of each set of open-ended questions, the interviewer recounted to the respondent the points she brought up and asked if the factors discussed had ever functioned as barriers to her care. Free listing domains included Health Maintenance (e.g., "What are some things people do to stay healthy?", "What are some things you do to stay healthy?"); Barriers to Care (e.g., "What are some things that might make it too hard for a woman to get care if she were sick?", "What are some reasons a woman would not get a mammogram?") and Preventive Medicine (e.g., "What are some things that you eat, drink or take to keep from getting sick?", "What are some reasons that you might want to take a medicine to keep you from getting a disease before you are sick with it?", and "What are some things that you would do to keep from getting breast cancer?")

Originally, we had planned to conduct future, separate interviews with an additional 40 women, separate from the first sample of 40 women, who were to be recruited through the referral chains after interviews had been completed and analyzed for the first respondent sample. The purpose of this step was to list the factors and themes identified most frequently as barriers to care among the first group and take this list to the second sample. The second group would then

be asked to agree or disagree that these factors were important barriers to care and use paired comparisons to rank the factors in terms of their relative importance as barriers to screening mammography. This would allow us to establish a consensus as to the salience of factors and themes identified as barriers to care in the first group, as well as a sense of how the complex interplay of these factors resulted in decision making regarding breast cancer screening and prevention. However, we made the decision to alter this methodology. We consolidated both the semi-structured interview process and the relative ranking steps described above into a single step within the semi-structured interview process for greater efficiency. Consensus was analyzed with a statistical software package (Anthropac) which measured the amount of intra-group variability regarding common factors among this group of respondents. Analysis is highly reliable with a subject population of 40 respondents [2].

In addition to audiotaping the interviews, interviewers also wrote fieldnotes following each interview, to make note of any dynamics, situational biases, themes that emerged during the course of the interview, or any other rich information that could serve to contextualize the data or identify problems and earmark the data for exclusion from analysis at a later date.

We conducted interviews with a convenience sample of 29 urban women throughout Philadelphia, 40 years and older who, if between the ages of 40 and 50, had never had a baseline mammogram, or who if aged 50 and older, did not get annual mammograms. Twenty four of the women were African-American, 4 were Caucasian, and 1 was Chinese-American. Socioeconomic status (SES) was measured on a per-capita basis, with overall family income divided by number of family members supported by that income. Average per-capita income was \$7,279 for African American women vs. \$12,083 for Caucasians.

Data Coding and Analysis:

Two research assistants, working together with the project manager, transcribed audiotaped interviews. When the research assistants were unable to understand words or phrases muffled due to background noise or lowered voices, the interviewer who had conducted that particular interview and the Project Manager interpreted. If the interviewer and project manager were unable to understand the word or phrase, then place markers were inserted in the text of the transcript.

For coding and analysis purposes, free listing exercises were entered into Anthropac 3.22, and the transcripts of open-ended interviews were imported into NUD*IST NVivo. To facilitate ongoing, rapid comparison of specific topics among transcribed interviews, the project manager established broad coding categories based upon the structure of the data gathering guide (e.g., Health and Wellness, Preventive Care, Sick Care, Mammograms, Structure of Medical Encounters, EMs of Cancer). Free listing exercises were used as the first point of triangulation of data analysis. Triangulation is conducted to ensure consistent interpretation of raw data across a sample.

The investigators and the project manager met to identify and discuss specific coding categories based on *a priori* knowledge of mammography-related decision making and barriers to care, hypotheses, and emergent issues raised by the respondents. Each of the above broad coding categories encompassed a set of *a priori* codes decided upon during this

meeting. *In vivo* codes were established within broad coding categories, where applicable, or as separate, free codes, as patterns and themes emerged from the data [3].

The project manager generated broad, cross-case searches of the aggregate data codes to identify the most prevalent themes pertaining to coded categories. Notable exceptions were identified and set aside as case studies for comparison to the majority. Variations on themes were discussed and investigators reached a consensus as to how the theme in question should be characterized.

Additionally, the project manager used content analysis to analyze cases on a one-by-one basis, identifying themes important to each individual and generating a series of "case models" for understanding each individual's health-related behavior. The project manager then compared these models and themes across cases, mapping them one on top of the other, looking for common points of fit. Content analysis was used as the second point of triangulation of data analysis.

Interviews were analyzed both individually and in aggregate for revealing linguistic use. Linguistic devices, such as words, metaphors, word play and sentence structure can provide insight into the context of meaning [4]. Narrative analysis is a standard methodology for revealing such linguistic devices [5, 6] and was used as the third point of triangulation of data analysis.

Key Research Accomplishments

- Focus Group Discussions
- Literature review
- Critical Review of Data Gathering Guides
- Pilot Interviews
- Final development of survey instruments
- Development of system of identification and recruitment of respondents
- Development of data management system and data coding system
- Enrollment of respondents into study
- Initiation and continuation of data collection
- Management of referral tree system
- Interview transcription and coding
- Data analysis
- Analysis of efficacy of sampling strategy
- Analysis of barriers to mammography
- Analysis of African-American respondents' data
- Awarded funding for comprehensive research into potential cultural model of health maintenance and disease prevention among low-income African Americans.

Reportable Outcomes

The following reportable outcomes have resulted from this work:

1. Abstract: E. Micco, L.T. Dean, K. Armstrong. **Perceptions of Health as a Homeostatic Condition and Barriers to Tamoxifen Use Among Urban African American Women.** Presented at The Eunice and Irving Leopold Annual Scientific Symposium and Retreat, March 26, 2002. (Appendix F)
2. Grant Award: **Cultural Model of Prevention in African-American Women**
R-21 Behavioral Oncology, Submitted to NIH, June 1, 2002. P.I. Katrina Armstrong, MD, MSCE. Co-Investigators: James C. Coyne, PhD; Chanita Hughes, PhD; Rebecca Huss-Ashmore, PhD. (Appendix G)
3. Manuscript: Micco E. **Pollution, Purity and Prevention: Concepts of Body Function and Disease Prevention Among Low-Income African American Women.** In Submission.

Conclusions

Analysis of both the data and the efficacy of the sampling method yielded several important conclusions. These are discussed below in order of immediate relevance to study aims.

SAMPLING:

We were able to analyze the effectiveness of the referral tree (snowball sampling) methodology through both referral tracking and informant behavior and stated opinion. Although we did not systematically collect informant opinions regarding the sampling strategy, informants did comment upon the sampling method, indicating their approval or disapproval of the system. Interviewers and research assistants documented these reactions in fieldnotes and on intake and tracking forms, respectively.

We found snowball sampling to be ineffective for research into underservedness re cancer for several reasons. First, many women refused to refer us to any one who fit the study criteria, citing the referral as socially "inappropriate." Second, women who did provide referrals often did not provide us with appropriate referrals. Referral tracking revealed that informants frequently referred us to individuals who did not fit study inclusion criteria. Informants were asked to refer interviewers to "Women forty and over who don't get mammograms, and/or who don't go to the doctor for any reason." Some informants provided multiple referrals to women well under forty, one routinely provided referrals to women who get regular mammograms AND regularly visit physicians, and one informant referred us to two men.

Several issues may have contributed to this problem. It is possible that inappropriate referrals were sometimes a result of a miscommunication between the interviewers and the informants. In studies of IV drug users where snowball sampling has been successful, a single criterion for inclusion (i.e. IV drug use) may have simplified the referral process for informants. In contrast, we required three criteria for inclusion. This may have made the task more complex, resulting in a greater number of ineligible referrals. However, content analysis of intake forms and narrative analysis of fieldnotes and interview demonstrate that, at least among African American women, additional possible explanations for inappropriate referrals should be taken into account.

African American women, while much more demonstrably willing to provide any referrals than any other group, were unique in providing "substitute" or proxy referrals; rather than providing us with referrals to eligible family and friends they discussed specifically within the context of their interviews. Eligible women who both did and did not consent to be interviewed practiced this "gate-keeping" mechanism. During interviews, women gave repeated and consistent examples of eligible family and friends' eschewal of mammography and medical care. In their fieldnotes, interviewers took down these individuals' names, ages and relationship to the informant. Interviewers wrote these individuals' names on study flyers and, at the end of each interview, specifically requested to be referred to these eligible candidates, handing informants the addressed flyers. However, only one woman who mentioned relatives or friends who fit the study criteria consented to refer those individuals. Most women who spoke about their relatives and friends referred us (if they referred us to anyone at all) to neighbors who most often did not fit the study criteria, or offered to post our flyers instead of providing direct referrals.

It is possible that etiquette based on distrust of the health care system in general was breached by our referral request. One woman said she knew it would "get her in trouble" but that she wanted to help out with our study, and so gave us the telephone number of an appropriate referral. When the interviewer contacted this potential informant, she responded by saying, "Now, she knows better than to give out my number!" When the interviewer apologized and explained the nature of the study, the informant replied that she distrusted the health care system and that too many people call wanting her to participate in studies. She eventually completed a short interview, providing important information to this study, but preferred to conduct the interview over the phone so that she would not have to travel to the University of Pennsylvania Medical School. She explained that she refuses to come to Penn's campus because she boycotts medical research facilities. Many of the women who proactively volunteered to participate in this study similarly distrusted or were hostile toward (variously) male doctors, the motives of primary care physicians relative to insurance reimbursement, pharmaceutical corporations and the efficacy of their products, and research in general. While none of these concerns were sufficient to prevent their participating in our research study, it is possible that for a variety of personal and social reasons study participants did not wish to assume that their eligible family and friends would be similarly willing to participate in this study.

Distrust may not be the sole reason for non-referrals; narrative analysis of interview data suggests that shared explanatory models of cancer may also have contributed to women's reluctance to provide referrals for this study. An explanatory model of disease is a cognitive functional model any individual may have of disease etiology, symptomology, expected progression, expected duration, and expected outcome (Good & Kleinman, 1978). Such models may be local to the individual; for example, in their seminal work on explanatory models of disease, Arthur Kleinman and Byron Good described the case of the wife of a plumber who conceptualized her alimentary system as household plumbing (1978). However, explanatory models of disease are also frequently shared among people defined as cultural or social groups. Explanatory models are informed both by empirical observation and social patterns and expectations. For example, many prevailing infectious disease theories in the antebellum South were predicated upon theological constructs associating purity, sanctity and innate cleanliness with Whiteness and innate immorality and godlessness with all other races (Savit, Fett, O'Connor).

Prior studies have reported various culturally and socially based explanatory models of breast cancer, speculating that they might account for eschewal of mammography (Chavez, 1988). In order to understand if among underserved women these explanatory models *do* in fact account for eschewal, of mammography, we developed general questions corresponding to the elements of an explanatory model (above) and systematically inquired if any of the stated elements did then, had in the past, or might in the future, contribute to eschewal of mammography. Informants did cite several of these elements of their explanatory models of cancer as barriers to mammography; these will be discussed in the next section. Relative to the effect of explanatory models of breast cancer on snowball sampling for this study, several themes emerged across the entire sample that point to a shared conception of cancer as a taboo subject. This taboo may be responsible for unwillingness among participants to refer us to eligible friends and family members who could have participated in this study.

Respondents described cancer as an incurable disease that is usually not ever discussed among family members or between friends. Women explained that within kin and social groups, cancer was either not discussed or discussion was

limited to brief initial communication of the fact of disease. One woman's succinct comments were highly representative of the sample:

Interviewer: Did your aunt or grandmother ever discuss their breast cancer with you?

Participant: No.

I: No. Anybody in your family?

P: No. It's a taboo subject. Not up for discussion.

Informants who maintained that cancer is a taboo subject explained that women in their family who developed breast cancer relied on the common discourse of African American female strength to preserve their functionality in the face of cancer and shield their family members from their disease status. Although one informant directly attributed her family's taboo against discussion of cancer to this strength, the discourse of female strength provides only an adequate mechanism for the propagation of the taboo, not for a rationale behind its development and meaning. The explanatory model of cancer shared among these informants, however, does offer insight into the taboo's meaning and origin.

When asked, as a part of inquiry into their explanatory models of breast cancer, how breast cancer starts (etiology), 55% (N=11) of all respondents, including those for whom cancer was a taboo subject, stated that they preferred not to think about it, that having cancer should not be pre-conceptualized. This was generally expressed as a wish to keep "negative thoughts" from replacing or corrupting present "positive thoughts," which are thought to actively preserve good health. The following is an example of this belief system:

I: Have you ever thought what having breast cancer would be like?

P: Uh-uh.

I: Never imagined it or -

P: Uh-uh. No. I try to keep those negative thoughts away from me.

Of this sub-sample, seven women explicitly stated that pre-conceptualization of disease can "bring on" the very disease being contemplated or discussed. As cancer is considered to be an incurable disease, discussion of cancer or the presence of cancer within the home may be considered to be detrimental to the entire family. For example, one African American community leader who was a breast cancer survivor and women's health advocate referred her sister, who refused mammograms and had not seen a physician in several years, to our study. The informant discussed the impact of her sister's decision to speak about her cancer with her and her other sisters. The informant explained that what her sister regarded as an important warning, she and her other sisters regarded as a kind of curse. She explained to the interviewer that her sister's diagnosis "brought cancer into the family," and she and her sisters resent being forced to contemplate cancer lest they develop breast cancer.

It is possible that this belief functions with high importance within many different social groups' explanatory models of cancer. Although we found this belief primarily among the African American women who informed our study, this belief is not unique to African American women. In her book, *Cancer, Causality and the Community*, Martha Balshem traces the prevalence and public health impact of this belief among lower-income Philadelphia Caucasians of primarily Polish, Irish and German descent.

Given this belief, being asked to discuss cancer in any context with a friend or family member may cause a feeling ranging from mild discomfort to extreme wariness and might cause unwillingness to refer family and friends to a study focusing on breast cancer. This element of our subject sample's shared explanatory model of breast cancer may therefore contribute to the reasons that snowball sampling proved to be an inefficient method of sampling for a study focusing on medical underservedness relating to breast cancer.

PURITY, POLLUTION AND PREVENTION:

During content and narrative analysis of transcribed interviews, several broad, unifying concepts emerged that suggested that the African-American women in our sample shared a conceptual preventive health framework that could have strong implications for mammography utilization as well as adoption of breast cancer chemoprevention, such as tamoxifen. The concepts below apply only to the domain of preventive medicine and are not generalizable outside that domain. These themes are outlined below in Table 1:

Table 1: Cultural Categories and Theories of Disease Prevention

Category/Theory	Number Respondents Cited	% Sample (N=20)
Body as a natural system	8	40
1. sickness drags body off balance	3	15
Medical Care		
1. Air causes cancer to grow/spread	8	40
2. Med intervention disrupts body system	8	40
3. Doctor visits are only for sickness	6	30
Medicines		
1. Pharmaceuticals are "too strong"	14	70
2. Good Medicines act quickly	14	70
3. Good Medicines are natural and gentle	14	70
4. Medicines are only for sickness	6	30
Thinking:		
CAUSES DISEASE		
1. "Worrying" about developing disease	12	60
2. Taking prophylactic medications	8	40
3. Considering curative measures in anticipation of future disease	7	35
PREVENTS DISEASE		
1. Avoiding thoughts about future disease	11	55
2. Getting multiple medical opinions	6	30
3. Learning natural ways of keeping well	5	25
Stress/Overexertion		
1. Too much mental stress causes disease	8	40
2. Too little mental activity causes disease	7	35
3. Physical overexertion causes disease	7	35
4. Being lazy or trifling causes disease	7	35
Social Transgressions cause disease	5	25

The Body as a Natural System: Respondents highlighted and explained illness experiences throughout their narratives. The majority of respondents described their bodies as "natural" systems which if left alone will take care of most diseases themselves in due time. Cancer was conceived of as a "livable disease," meaning that as long as no surgery and adjuvant therapies were administered, a person could cope with the pain better and live longer than if surgery and other medical

therapies were administered. Coding searches revealed that a proximate relationship between the concepts of the body as natural and the introduction of air into the body during surgery causing cancer to spread occurred in 8 of 20 interviews, suggesting a cognitive association between the two concepts. Any medical intervention was described as “messing with [one’s] body” which could cause or hasten death from cancer. A minority of respondents who shared the above views also described illness as feeling “off-center,” “thrown off,” or “dragged down” (N=3). Use of a spatial metaphor implies that these respondents viewed their bodies as operating in a balance/counterbalance which illness negatively impacts. This view was not representative of the sample.

Several cultural theories were identified that could disrupt the body’s homeostasis and lead to the development of illness. These included:

1. Medical Care: Respondents reported that medical interventions are only for when you are sick. Although respondents were aware of what checkups or annual physicals are, they cited that they were not necessary. As noted above, visiting doctors unnecessarily can cause disease, worsen illness, and even hasten death because medical intervention in general, particularly surgery and pharmaceutical therapies, can interfere with the body’s natural order (homeostatic condition) and as such is possibly iatrogenic (N=8, 40%). Further, respondents believed that mammograms in particular could cause cancer through mashing the breast and radiation exposure (N=7, 35%) These respondents felt that the surgery involved in treating many diseases, particularly cancer, would cause more rapid decline than would be experienced if one were to leave the disease to progress along its natural, inevitable course. Some other mechanisms through which cancer is thought to occur are bodily injury, such as mashing or poking the body; exposure to pollutants such as radiation or toxins such as pharmaceuticals; eating processed, non-natural food; and the pollution of the body with air, which is thought to cause all living things to grow and thus allow cancer to spread unhindered through the body. These culturally based beliefs were made all the more complex by the social effects of frustration over frequent, contradictory media-based communication regarding carcinogens and the efficacy of mammography.

2. Medicines: Respondents were concerned about putting pharmaceuticals into their bodies. The primary reason for taking pharmaceuticals was, according to respondents, immediate or quick relief of illness or pain. There were two cited components of this concept that have implications for chemoprevention utilization in particular among the preventive strategies we investigated:

- **Good/Bad Medicines:** Respondents repeatedly grouped medicines into two categories: Good Medicines and Bad Medicines (N=14, 70%). While an excess of any medicine was considered potentially harmful to the body, Good Medicines are considered “natural,” and “gentle,” are thought to resolve illness quickly; and have no discernable side effects. Cited examples of Good Medicines are: aspirin, Tylenol, quieting cough syrup, cod liver oil, herbal supplements, and vitamins. Pharmaceuticals generally fell into the Bad Medicine category because they don’t resolve illness or pain quickly, are “too strong” (have powerful side effects), and can have iatrogenic effects (cause worse or more disease than what they were meant to cure). However, although they are prescription drugs,

the majority of the respondents (N=13, 65%) grouped antibiotics into the category of Good Medicines. Bad Medicines were considered “toxic” and could disrupt the body’s natural order, causing more disease to occur. The classification of pharmaceuticals as Bad Medicines was also linked to significant distrust of the economic interaction among HMOs, pharmaceutical companies and physicians (N=13, 65%).

- **Medicines Mean Illness:** Respondents reported that prescription medicines are “serious business” and should be taken only for illness. When a person feels better, it is appropriate to stop therapy, because medicine is only for when you are feeling bad, not for when you are feeling fine (N=6, 30%). All of the six respondents who reported that prescription medicines should only be taken for illness also reported that doctor’s visits are for illness only, and checkups or annual physicals are unnecessary. This association may demonstrate a structural similarity or relationship between the two concepts [7].

3. Thinking: Respondents reported that illness can result not only from accidental injury; medical intervention such as mammography; and exposure to external pollutants such as radiation, toxic medications or processed food, but also from imagining or pre-conceptualizing future illness episodes. Conversely, avoiding any thought of future disease was thought to aid in maintaining health. Respondents classed these two elements as Negative and Positive Thinking. Both of these concepts are detailed below:

- **“Negative thinking”** about future disease played a role in the majority of the African-American respondents’ EMs of disease (N=13; 65%). The women did not equate negative thinking and stress, citing the two separately. Stress was defined as worry over bad conditions in one’s life, or “too many troubles.” Respondents acknowledged that stress could “drag [a person] down” creating a physical condition in which a number of diseases could occur. Negative thinking about a particular disease or illness experience was different however, in that it could directly “bring on” that specific illness. Behaviors cited as indicative or symbolic of Negative thinking were, in order of frequency of occurrence across the sample:
 - “Worrying” about one’s risk of developing disease (N=12, 60%)
 - Taking prophylactic medications for a specific disease (N=8, 40%)
 - Screening for cancers (i.e. mammography) (N=12, 60%)
 - Considering curative measures to take in the event disease occurs in the future (N=7, 35%)
- **“Staying Positive”** which the majority of respondents (N=11) defined as avoiding thoughts about a disease prior to having it, is a possible counterbalancing mechanism to negative thinking. A subset of these respondents also associated staying positive with being “proactive” about one’s health. None of the behaviors associated with staying positive were explicitly cited as having any direct role in restoring health. Behaviors cited as indicative or symbolic of staying positive were, in order of frequency of occurrence across the sample:
 - Avoiding thoughts about a disease (prior to having the disease) (N=11, 55%)

- Educating oneself regarding the best way to treat existing conditions (including seeking multiple opinions from medical and holistic practitioners) (N=6, 30%)
- Educating oneself regarding “natural” ways of keeping well (N=5, 25%)

4. Balance of Stress/Physical Work: Respondents reported that avoiding mental stress, classified as dealing with “too many troubles,” was key to maintaining health (N=8, 40%). Similarly, physical overexertion was linked to “straining something” or bodily injury, which could later turn into cancer (N=7, 35%). While overexertion was an explanation for sickness, respondents also noted that lack of mental or physical work was also capable of producing sickness (N=7, 35%). Thus, the key to health may be visualized as a dual set of balances. The first set of balances is between mental inactivity and mental overexertion (dealing with too many troubles) and physical inactivity (being lazy or “trifling”) and physical overexertion (“straining something”). The second balance is that between the mental and the physical, the mind and the body. As one respondent put it, “Good frame of mind is good for the body. It keeps your immune system... I just try to stay positive, eat right, make sure I have my balance, which I grew up on. And I keep that up.”

5. Social Transgressions Cause Cancer: Five of the seven respondents (25% of overall sample) who cited bodily injuries caused by physical exertion as causative of cancer explained that such injuries could result from stepping outside normal social boundaries (playing baseball with boys, nursing children too long, being a “workaholic,” or performing a man’s physical labor). The research team classed these physical injuries separately from physical injuries caused by medical intervention. Injuries incurred by exertion have different meaning as they contain the added context of breached socio-normative expectations. This transgression implies morally-based social impurity [15] which can disrupt the body’s natural condition as opposed to simple accidental injury such as accidentally being hit in the breast by a child’s fist or hitting a breast on an object. Although studies exploring the role of EMs of disease elicited accidental injury of the breast as a possible mechanism for the onset of breast cancer, the women in our sample more consistently cited injury resulting from social transgression as a mechanism for the onset of breast cancer.

C.3: Discussion:

The themes that emerged within interviews and across our sample were all cited by the respondents as being important to their decision making regarding screening mammography and clinical breast exams. It would be valid to take these themes as discrete elements or loosely related cultural theories that independently and additively contribute to avoidance of preventive care [8]. However, this analysis would be incomplete. Limiting analysis to enumerating these themes as independent barriers to care would gloss over the structural similarities inherent among the themes as well as deny the supporting relationships among them and the interpretive meanings of these relationships the women made efforts to convey to the researchers. These supporting relationships argue in favor of interpreting the themes that emerged from interviews as elements of a cultural model.

Negative thinking, for example, was cited proximate to Positive thinking in the narratives of all 11 respondents who discussed Positive thinking. The nature of these proximate citations frequently centered on a theory of replacement:

because Negative thinking, which is primarily conceived as avoiding thoughts about future disease, can “bring on” the very disease one was imagining, the only logical way to maintain health is to “think positively.” Disease prevention includes avoiding Negative thinking.

Avoiding thinking about future disease is conceptually and structurally similar to the concept that medicine and medical visits are for sick care only. Respondents believed that visiting doctors when well and getting routine (annual) screening mammograms were examples of “looking for trouble” and that this act of worrying about a disease (i.e. breast cancer) not troubling you presently could directly “bring on” breast cancer.

Because medical visits are for illness only, and because the respondents regarded prescription medicines as appropriate therapies for acute illness, for them, medicines mean illness. Through both ethnomedical studies of symbols employed in medical and magical healing [7, 9, 10] and documentation of limited but significant patient response to placebos, especially in regard to pain and discomfort management [11-13], it has been demonstrated that medicines do more than address the biological basis of disease. They also concretely represent the meaning of healing and are expected to work to restore health. In a word, they are symbols [14]. Taking into account the place of Negative thinking within the African-American model of disease prevention, as symbols of illness, preventive medicines might be expected to cause the illness they were meant to ward off. Accordingly, six respondents in our sample cited taking preventive medicines as examples of Negative thinking. This expectation or assigned symbolic meaning may act as a barrier to uptake and use of chemoprevention.

As demonstrated by the results, although respondents did not use the exact term homeostasis to describe their concept of body function nor did they explicitly acknowledge actively trying to establish or maintain an internal homeostatic condition, their language strongly suggested that they conceptualized the body as optimally functioning as a homeostatic system that can be disrupted either physically or psychically if it is polluted by “toxins”. Disease prevention is conceived of as maintaining the purity of that system by avoiding pollution and attempting to cleanse these toxins from the body. Below are some excerpts from interviews, chosen for their overall representation of the sample:

(Interview #5)

Respondent: Drinking a lot of fluids, you feel like that flushes a lot of toxins out your body, which I also think could be a probably cause for cancerous cells, toxins, too much food in your body can build up in the bloodstream.

Interviewer: Do you take anything to stay healthy?

Respondent: Nope. No. I don't take nothing. I don't mess with my body. I was taking iron pills 'cause my blood count would drop. Only they give me is the tenenol, and that's for my heart not to race, 'cause I have heart murmur.

(Interview #12)

Interviewer: Can you tell me some reasons why a woman might not want to take medicines, to keep from getting sick?

Respondent: Because she may not ever have what she's taking the medicine to prevent for, so why just toxicise my body without need? You've got to show me the proof that we've found a spot that's malignant. Then, okay, then we're going to try to prevent its spreading. That's what we'll do.

(Interview #19)

Respondent: I don't think I want to take anything until I, you know, till the drugs is even necessary. I don't want any chemicals or drugs in my body.

Interviewer: What do extra drugs and chemicals in your body do?

Respondent: Well it sure ain't good for you. And anything that ain't good for you ain't natural. It means it's a foreign substance.

The respondents conceived of the body as "natural." Ingestion of "toxic" pharmaceuticals is a non-natural behavior as it can "mess with your body." Respondents frequently used the key words, "toxic" and "foreign" to describe the qualities of substances they perceived as having a negative effect on the body's natural homeostasis; these words are traditionally associated with the concept of pollution throughout diverse cultures [15]. As it is deployed in the African-American disease prevention framework, pollution is a complex concept in that it can be conceived of as anything from negative thinking to air being introduced through surgery to medical intervention of any sort (mammograms and their associated radiation in particular) to pharmaceuticals to a breach of social norms to any complex combination or interplay of those factors. For instance, surgery is a pollutant that can disrupt the body's natural homeostatic condition through a combination of bodily injury and the introduction of air into the system. Pollution may be countered by introducing purity into the system. "Good medicines" were consistently described as being "natural." The quality of "naturalness" is a construct that is associated with purity, particularly in industrialized societies [16, 17]. Further, the concept of unnatural, "foreign" substances being introduced into the body echoed other comments about the possibility of injury due to social transgression such as doing work foreign to one's gender status or social expectations causing breast cancer. Social transgression and immoral behavior are strongly implicated means of pollution and hence disease in many cultural traditions, including African American health traditions [17-19]. It is clear that the above postulated disease prevention framework above strongly incorporates a purity/pollution construct.

Our preliminary research shows that the model identified in our preliminary work may share more essential points with models identified by other studies described above than with a biomedical model of disease prevention. For example, Mathews et al found that the individuals they interviewed thought of antibiotics as good medicines because they cleanse the blood of impurities. The women in our sample routinely grouped antibiotics with good medicines, but it was beyond the focus of this study to elicit the logic behind this categorization. It has been well documented that the belief among

African-Americans that air entering the body through surgery can cause it to spread. This mechanism is generally explained through the use of agricultural metaphors such as air being an agent of growth and causing the cancer to grow unhindered in the body [20, 21]. Of the eight women in our sample who discussed this concept, seven used agricultural metaphors to describe the process. Mathews and Snow noted that the Southern African-American women in their studies believed that illness not able to be quickly resolved through home remedies or biomedical intervention are unnatural in origin, or have their cause in magic or malicious spells [22, 23]. While the women in our sample did not attribute cancer to malicious spells or intentional magic, the concept that pre-conceptualization about a disease like cancer could "bring it on," or conjure up that disease, might have its roots in a magical tradition. It is also possible that the preference demonstrated among the women in our sample for medications that quickly resolve illness may be related to this "natural/unnatural" disease concept. Finally, both the women in Mathews' study and our sample attributed disease to social transgression [24].

This is not to say that the African-American model of disease prevention is entirely exclusive of the biomedical model of health. However, it may be distinct enough from the biomedical model of health that fit between the two models may be lacking.

This postulated African-American model of disease prevention distinctly contrasts with the model of disease prevention represented by mammography and chemoprevention. According to the above, the body functions ideally in a homeostatic condition, and illness is experienced or disease is created when this homeostasis is disrupted. It is easy to see the lack of fit between the two models, as demonstrated below:

With their focus on preventing a disease it is potentially harmful to consider at all, getting annual mammograms or taking chemoprevention daily are representative of Negative thinking. Medications, serious substances that are foreign substances, potentially polluting or toxic to the natural order of the body, are used according to the African-American model postulated above only for treating illness. As such, medication means or symbolizes illness. By polluting the body and negative thinking, chemoprevention could, therefore even be thought to bring about breast cancer, an interpretation that would be supported by a single news report or story about a woman who was diagnosed with breast cancer despite having completed the full preventive regimen. Chemoprevention may also have side effects: the drug could be perceived according to the above model as being "too strong" and therefore representative of the toxic, polluting nature of the drug, which would argue for its immediate discontinuation. Additionally, the 5 year course of treatment that is currently recommended for tamoxifen does not fall into the model of quick resolution of illness or pain that would be deemed acceptable for use of medication. Mammography, in that it flattens the breast, is seen as causing injury that could cause breast cancer. Further, the radiation used in mammography could be thought of as a pollutant which can cause breast cancer rather than prevent it. Exposure to annual mammograms would not be part of a logical health maintenance model according to the African American cultural model of health prevention described above. Current biomedical explanations of chemoprevention do not incorporate themes of cleansing the body or restoring homeostasis, nor do current biomedical explanations of mammography incorporate themes of mammography as normative, socially correct behavior. Both

cleansing and practicing normative, socially correct behavior were shown to be important components of disease prevention in our data. A failure to understand these factors would severely limit physician-patient communication about the need for annual mammograms and the decision about chemoprevention, potentially leading to adverse consequences for the physician-patient relationship and leaving unresolved the problem of undue burden of cancer among African-American women.

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Appendix A: Pilot Data Gathering Guides

Code

- 28 -

- ☐ High school grad/ GED
- ☐ Some college or technical school
- ☐ Graduated college
- ☐ Graduate or professional school

9. What is your current marital status:

- ☐ Married or living as married
- ☐ Never married
- ☐ Divorced
- ☐ Separated
- ☐ Widowed
- ☐ Other: _____

10. Do you work outside the home for pay?

- ☐ Yes ☐ No

Do you have more than one paid job outside the home?

- ☐ Yes ☐ No

If yes ➤ Please list the types of jobs you have (for example, "lawyer" or "secretary")

1. _____
 - How many hours per week do you work at job #1? _____
 - How many months have you had job #1? _____
2. _____
 - How many hours per week do you work at job #2? _____
 - How many months have you had job #2? _____
3. _____
 - How many hours per week do you work at job #3? _____
 - How many months have you had job #3? _____

11. Does your work ever keep you from seeking health care for yourself? ☐ Yes ☐ No

12. How many children (under age 18) live in your household? _____

13. Is there someone you can rely on to watch your children if you need to go to the doctor? ☐ Yes ☐ No

14. Are there any sick or disabled adults living in your household that you take care of? ☐ Yes ☐ No

15. Are you caring for any sick or disabled adults living outside your household? ☐ Yes ☐ No

16. Are you giving financial support to anyone living outside your household? ☐ Yes ☐ No

If yes ➤ Please tell us about the kind of support you provide:

- ☐ elderly relative (Nursing home, in-home care)
- ☐ ex or current husband (alimony, spouse support)
- ☐ child/children (child support, school tuition, helping adult children)
- ☐ other (please describe) _____

17. Does caring for people inside or outside your household ever keep you from seeking health care for yourself?

☐ Yes ☐ No

18. Do you go to any kind of health care provider when you are sick? (please choose all the ones you use)

☐ I do not go to any kind of health care provider when I am sick.

- | | | |
|--|--|--|
| <input type="radio"/> Acupuncturist | <input type="radio"/> Family physician (MD/DO) | <input type="radio"/> Midwife/Doula |
| <input type="radio"/> Ayurvedic practitioner | <input type="radio"/> Gynecologist | <input type="radio"/> Naturopath |
| <input type="radio"/> Chiropractor | <input type="radio"/> Herbalist | <input type="radio"/> Nurse practitioner |
| <input type="radio"/> Curandera(o) | <input type="radio"/> Hypnotherapist | <input type="radio"/> Specialist (e.g. Cardiologist) |
| <input type="radio"/> Faith healer | <input type="radio"/> Massage/Touch Therapist | <input type="radio"/> Physical Therapist |
| <input type="radio"/> Other: _____ | | |

19. Think about all the times you've been to a health care provider to take care of yourself when you are sick, from this time last year until today. Do you always go to the same place (for instance, the same doctor's office, clinic, emergency room, or healer's home)?

☐ Yes ☐ No

If yes ➤ do you always see the same health care provider (for instance, the same doctor, healer, chiropractor?) ☐ Yes ☐ No

20. Do you go to any kind of health care provider to keep well? (please choose all the ones you use)

☐ I do not go to any kind of health care provider to keep well.

- | | | |
|--|--|--|
| <input type="radio"/> Acupuncturist | <input type="radio"/> Family physician (MD/DO) | <input type="radio"/> Midwife/Doula |
| <input type="radio"/> Ayurvedic practitioner | <input type="radio"/> Gynecologist | <input type="radio"/> Naturopath |
| <input type="radio"/> Chiropractor | <input type="radio"/> Herbalist | <input type="radio"/> Nurse practitioner |
| <input type="radio"/> Curandera(o) | <input type="radio"/> Hypnotherapist | <input type="radio"/> Specialist (e.g. Cardiologist) |
| <input type="radio"/> Faith healer | <input type="radio"/> Massage/Touch Therapist | <input type="radio"/> Physical Therapist |

o Other: _____

21. Think about all the times you've been to a health care provider for yourself, to keep well, from this time last year until today. Do you always go to the same place (for instance, the same doctor's office, clinic, or healer's home?)?

o Yes o No

If yes ➤ do you always see the same health care provider (for instance, the same doctor, healer, chiropractor?) o Yes o No

22. How would you rate your chance of developing breast cancer? *Please check a box below*

o very low o moderately low o neither high nor low o moderately high o very high

23. How often do you worry about developing breast cancer?

Please circle a number below

1	2	3	4	5	6	7
Not at all						All the time

24. A mammogram is an x-ray taken only of the breasts by a machine that presses against each breast while a picture is taken.

➤ Has a health care professional ever told you to have a mammogram? o Yes o No

➤ Have you ever had a mammogram? o Yes o No o Not Sure

➤ Was this the only mammogram you have ever had? o Yes o No

➤ If you have had at least one mammogram, when was your last mammogram? _____

➤ How many mammograms have you had in the past 5 years? _____

➤ Where do you get your mammograms? (please choose all you have used in the past 5 years)

o Free clinic	o Radiology or Imaging center	o Other _____
o Local hospital	o Van that visits neighborhood	

25. A breast exam is when a health professional uses his or her hands to feel your breasts for lumps.

When was the last time a health professional examined your breasts this way?

_____ o never
(month/year)

26. Have you ever felt your breasts for lumps yourself? o Yes o No

If yes ➤ how many times have you examined your breasts in the last 12 months? _____

27. Sometimes women say they feel more comfortable having a partner, boyfriend or husband examine their breasts for lumps. Has your partner, boyfriend or husband ever examined your breasts for lumps?

☐ Yes ☐ No

If yes ➤ how many times has this person examined your breasts in the last 12 months? _____

28. A PAP smear is a test done on the cervix at the time of a pelvic (internal) exam to screen for cervical cancer.

➤ Have you ever had a PAP smear? ☐ Yes ☐ No ☐ Not Sure

➤ If you have had at least one PAP smear, when was your last PAP smear? _____

29. Do you currently have health insurance? ☐ Yes ☐ No ☐ Not sure

If yes ➤ please check the type of plan that best describes your current health insurance:

- ☐ Fee-For-Service plan where you can go to any doctor or hospital
- ☐ HMO where your Primary Care Doctor refers you to specialists
- ☐ PPO where you can go to any doctor or hospital on a list without getting a referral
- ☐ Medicaid
- ☐ Medicare

30. How many adults currently live in your household? _____

31. Including income provided by you and all other people living in your household, what was your total household income before taxes last year?

☐ < \$10,000 ☐ \$10,000 to \$30,000 ☐ \$30,001 to \$50,000 ☐ \$50,001 to \$70,000 ☐ > \$70,000

33. How many people, including yourself, were supported by your household income last year? _____

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Left Blank**

Freelisting Exercises: Please tell us as many items as you can think of. There is no maximum or minimum number you have to tell us, and there are no right or wrong answers.

What are some of the things people do to keep well?

What are some of the things YOU do to keep well?

What are some of the words you would use to describe a mammogram?

Please tell me some reasons why a woman would *not* get a mammogram.

What are some of the reasons YOU would *not* get a mammogram?

Please tell me all the things that can cause breast cancer.

Code #: _____

STAND study: Pilot Data Gathering Guide

Note to the interviewer: Please make certain that your questions precisely follow this script. It is very important that we ask every woman we speak to the same questions, in the same way, in the same order. **Text in BLUE letters is not to be read aloud.** This text is meant to communicate only to you, the interviewer, and frequently indicates where you should ask conditional questions based on the informant's prior responses.

We're about to start our talk, I really appreciate your helping me out today. Although I am going to be asking a lot of questions, I want you to feel free tell me as much as you want to share with me. Sometimes, in a talk like this, we can get off the subject and spend a lot of your time talking about only a few things. Because I really want to get your opinions on all the things I have on my list, I may need to stop us talking about one thing and move to another. Please don't be upset with me if stop us talking about one thing and move on to another. We can always come back to what we were saying later, and we can share other stories at the end of this session, too.

I'd like to tape record our talk, just like the last time, because it really helps me remember what you say and keep your thoughts in your own words. Just like last time, everything you tell me is confidential. I will not share anything you tell me with Medicare, your insurance company, Welfare, Immigration, or any other agency. I will keep the tapes and any notes I take today in a locked file, in a locked building. No one will ever use your name in any data or in any paper written about this study. Is it all right for me to tape our talk?

I am going to start by asking you a few questions about getting care when you are sick:

People often go to different types of health care professionals when they are sick. I will read you a list of some of these professionals. Please tell me which ones you go to when you are sick. You can pick more than just one.

- | | | |
|---|--|--|
| <input type="radio"/> Acupuncturist | <input type="radio"/> Family physician (MD/DO) | <input type="radio"/> Midwife/Doula |
| <input type="radio"/> Ayurvedic practitioner | <input type="radio"/> Gynecologist | <input type="radio"/> Naturopath |
| <input type="radio"/> Chiropractor | <input type="radio"/> Herbalist | <input type="radio"/> Nurse practitioner |
| <input type="radio"/> Curandera(o) | <input type="radio"/> Hypnotherapist | <input type="radio"/> Specialist |
| <input type="radio"/> Faith healer | <input type="radio"/> Massage/Touch Therapist | <input type="radio"/> Physical Therapist |
| <input type="radio"/> Other: _____ | | |
| <input type="radio"/> I do not go to any kind of health care provider when I am sick. | | |

You said you visit a _____ (type provider) for sick care. How do you travel to see this health care provider? _____ (Ask for each provider listed)

When was the last time you went to see this provider? _____ (ask for each provider listed)

How long does it take you to travel to this health care provider? _____
k for each provider listed)

Why does it take you this long to travel to this health care provider? **(Ask for each provider listed)**

What do you see this provider for? **(Ask for each provider listed)**

Which of these providers do you prefer to see?

Why do you prefer to see that provider?

When we last talked, you said that you don't go to the same health care provider's office for sick care all the time. Why?

When we last talked, you said that you don't see the same health care provider for sick care all the time. Why?

Now I am going to ask you some questions about getting care as part of what you do to keep well.

People often go to different types of health care professionals as part of keeping well. I will read you a list of some of these professionals. Please tell to me which ones you go to keep well. You can pick more than just one.

- | | | |
|---|--|---|
| <input type="radio"/> Acupuncturist | <input type="radio"/> Family physician (MD/DO) | <input type="radio"/> Midwife/Doula |
| <input type="radio"/> Ayurvedic practitioner | <input type="radio"/> Gynecologist | <input type="radio"/> Naturopath |
| <input type="radio"/> Chiropractor | <input type="radio"/> Herbalist | <input type="radio"/> Nurse practitioner |
| <input type="radio"/> Curandera(o) | <input type="radio"/> Hypnotherapist | <input type="radio"/> Specialist <input type="radio"/> Faith healer |
| <input type="radio"/> Massage/Touch Therapist | <input type="radio"/> Physical Therapist | |
| <input type="radio"/> Other: _____ | | |

☐ I do not go to any kind of health care provider to keep well.

You said you visit a _____ (type provider) as part of keeping well. How do you travel to see this health care provider? _____ (Ask for each provider listed)

When was the last time you went to see this provider? _____ (Ask for each provider listed)

How long does it take you to travel to this health care provider? _____ (Ask for each provider listed)

Why does it take you this long to travel to this health care provider? (Ask for each provider listed.)

What do you see this provider for? (Ask for each provider listed)

Which of these providers do you prefer to see?

Why do you prefer to see that provider?

This next couple of questions is going to be about your health insurance. The first question is about using your health insurance when you are sick, the second question is about using your health insurance as part of keeping well.

When we talked last, you said you have a _____ health insurance. Are you able to use your insurance to visit your _____ (type provider) when you are sick? (ask for each provider listed)

Are you able to use your insurance to visit your _____ (type provider) to keep well?
k for each provider listed)

This next set of questions is about some answers you gave me the last time we talked together. I'll remind you what you said, and it will really help me out if you would tell me some more about that.

(This section should be personalized. The questions developed here will be posed only when appropriate to the answers the respondent gave during the demographic survey.)

When we last talked, you said that there isn't anyone you can rely on to watch your children if you need to go to your doctor(s).

- Who watches your children when you have other appointments (examples: work, classes, meetings, therapy)

sessions, agencies)?

- Do you mind taking your children with you when you go to the doctor?
- Do you mind taking your children with you when you go to other appointments?

When we last talked, you said that providing care for your family members or friends sometimes keeps you from seeking health care for yourself.

- Can you tell me which family members you need to care for?
- What parts of caring for them keep you from going to your doctor?
- Can you tell me which friends you need to care for?
- What parts of caring for them keep you from going to your doctor?
- Would caring for these people keep you from going to your doctor if you were sick?
- Would caring for these people keep you from going to your doctor to keep yourself well?

When we last talked, you said that your work sometimes keeps you from seeking health care for yourself.

- Can you tell me what parts of your work keep you from going to your doctor?
- Does your work keep you from going to your doctor if you are sick?
- Does your work keep you from going to your doctor to keep yourself well?
- Do you feel bad if you take time off from work?
- Do you worry about losing anything if you take time off from work? (examples: pay, respect, promotions)

Is there anyone else who keeps you from going to the doctor even if you don't need to care for him or her?

Are you worried about the doctor asking about your personal life if you go for care?

When we last talked, you said you thought your chance of getting breast cancer is _____ (low to high). Can you tell me why your chance of getting breast cancer is _____ (low to high)?

When we last talked, you said you worry _____ (range cited) about getting breast cancer. Can you tell me why you worry _____ (range cited)?

IF WORRY IS CITED: Can you tell me what some of the things you worry about are?

This next set of questions is about breast cancer. I am interested in your opinions about it.

Do you know anyone who has had breast cancer?

How did she think she got breast cancer?

How do you think she got breast cancer?

Are there other ways to get breast cancer?

What does breast cancer do to you?

What does (friend) say cancer did to her?

How does cancer spread?
Are there other ways cancer can spread?

How should breast cancer be treated?

Can you prevent cancer?
How can you prevent cancer?

Can you stop cancer once you have it?

Now I'd like to ask you some questions about some of the people you share health care information with.

Who in your family do you share health care information with?

Who in your family helps you make decisions about your health?

Who in your family disagrees with your decisions about your health?

How do _____'s feelings affect how you get health care? (ask for each family member)

Who in your neighborhood do you share health care information with?

Who in your neighborhood helps you make decisions about your health?

Who in your neighborhood disagrees with your decisions about your health?

How do _____'s feelings affect how you get health care? (ask for each neighbor)

Which of your friends do you share health care information with?

Which of your friends helps you make decisions about your health?

Which of your friends disagrees with your decisions about your health?

How do _____'s feelings affect how you get health care? (ask for each friend)

This next set of questions is about mammograms and breast self exams. A mammogram is an x-ray that is taken of your breast to see if there are any problems. A breast self exam is when you or your husband or partner feels your breasts for lumps.

Has anyone besides a health care professional ever told you to have a mammogram?

- Who?
- Did you follow this advice?
- Why?

If you didn't have a mammogram in the past 12 months, what were your reasons for not having a mammogram?

If you had a mammogram in the past 12 months, what were your reasons for having a mammogram?

You said that you examined your breasts for lumps ____ (# cited) times over the past 12 months. What were your reasons for examining your breasts for lumps?

You said you have never examined your breasts for lumps. What were your reasons for not examining your breasts for lumps?

Now I'd like to get your opinions on the health care you get when you are sick.

Think about this time last year until today.

- Over that time, have you ever felt that you couldn't get the sick care you would like?
- Why?

Is the care that you get when you are sick good enough?

- In what ways is it good enough?
- In what ways is it not good enough?

Does the care you do get when you are sick ever make you stay away from that health care professional?

Does the care you do get when you are sick ever make you put off or delay getting care from that health care professional?

Now I'd like to get your opinions on the health care you get as part of keeping well.

Think about this time last year until today.

- Over that time, have you ever felt that you couldn't get the care you needed to keep well that you would like?
- Why?

When you get care that helps you keep well, is it good enough?

- In what ways is it good enough?
- In what ways is it not good enough?

Does the care you do get as part of keeping well ever make you stay away from that health care professional?

Does the care you do get as part of keeping well ever make you put off or delay getting care from that health care professional?

Now I'd like to get your opinions on mammograms. **(ONLY ASK IF RESPONDENT HAS HAD A MAMMOGRAM)**

Think about your last mammogram. Was the care you got then good enough?

- In what ways was it good enough?
- In what ways was it not good enough?

Did the care that you got when you had your mammogram ever make you want to stay away from mammograms?

Did the care that you got when you had your mammogram ever make you put off or delay getting a mammogram?

That is the end of our survey. Thank you so much for answering all of these questions. I have a gift for you, as a way of saying "thanks."

Appendix B: Final Screening Tool and Final Demographic Survey

PIC #: _____

Interviewer: _____

STAND study: FORM A (For Interviewer)

Note to the interviewer: Please make certain that your questions precisely follow this survey/script. It is very important that we ask every woman we speak to the same questions, in the same way, in the same order. **Text in BOLD letters is not to be read aloud.** This text is meant to communicate only to you, the interviewer, and frequently indicates where you should ask conditional questions based on the informant's prior responses.

1. What year you were born? 19_____

2. What is the highest level of schooling you completed?

(READ THE LIST)

- 8 years or less ☐
- Some high school ☐
- High school grad/ GED ☐
- Some college or technical school ☐
- Graduated college ☐
- Graduate or professional school ☐

3. Are you: **(READ THE LIST)**

- Married or living as married ☐
- Never married ☐
- Divorced ☐
- Separated ☐
- Widowed ☐
- Other (specify below) ☐

4. Do you work outside the home for pay? o Yes o No **IF NO, SKIP TO #6**

➤ How many hours a week do you work at this job? _____

➤ How many months have you had this job? _____

5. Do you have more than one paid job? o Yes o No **IF NO, SKIP TO #6**

IF YES: ➤ How many hours a week do you work at this job? _____

➤ How many months have you had this job? _____

6. How many children under age 18 live in your household? _____

This section will help us understand your feelings about breast health.

7. Think about your chance of getting breast cancer. Would you say your chance is:

(READ THE LIST)

- Very low ☐
- Moderately low (or "pretty low") ☐
- Neither high nor low ☐
- Moderately high (or "pretty high") ☐
- Very high ☐

8. Think about how often you worry about getting breast cancer. Would you say you:

(READ THE LIST)

- Never worry ☐
- Worry every once in a while ☐
- Worry often ☐
- Worry all the time ☐

9. A mammogram is an x-ray taken only of the breasts by a machine that presses against each breast while a picture is taken.

➤ Have you ever had a mammogram? ☐ Yes ☐ No ☐ Not Sure

IF NO, SKIP TO #10

IF YES ➤ A1. Where do you get your mammograms? (please choose all you have used in the past 5 years)

- ☐ Free clinic ☐ Radiology or Imaging center ☐ Other _____
- ☐ Local hospital ☐ Van that visits neighborhood

IF MORE THAN ONE IS CHOSEN,

A2. At which one of these do you most often get your mammograms? _____

Why? _____

Which one do you like best? _____

A3. When was your last mammogram? _____ (month/year)

A4. Was this the only mammogram you have ever had? ☐ Yes ☐ No

➤ **IF A4 IS YES, SKIP TO #10**

➤ **IF A4 IS NO** ➤ How many mammograms have you had in the past 5 years? _____

10. A breast exam is when a health professional uses his or her hands to feel your breasts for lumps.

Has a health care professional ever examined your breasts this way? ☐ Yes ☐ No

➤ **IF NO, SKIP TO #11**

➤ **IF YES** ➤ how many times has she or he examined your breasts in the past 12 months? _____

Now we'd like to know a bit more about you.

11. Do you have health insurance right now? ☐ Yes ☐ No ☐ Not sure

12. Does your insurance pay for mammograms? ☐ Yes ☐ No ☐ Not sure

13. Have you ever been without any health insurance from this time last year until now?

☐ Yes ☐ No

14. How many adults live in your household right now? _____

15. Including your income and income from all other people living in your household, what was your total household income before taxes last year?

☐ < \$5,000

☐ \$5,000 to \$15,000

☐ \$15,001 to \$25,000

☐ \$25,001 to \$35,000

☐ > \$35,000

☐ Don't Know

☐ Prefers not to answer

16. How many people, including yourself, were supported by your household income last year?

Appendix C: Final Free-listing Exercise Sheet

STAND Study – FORM B (For Interviewer)

PIC #: _____

Interviewer: _____

I am going to ask you some questions about health care. Please tell me as many items as you can think of. There is no limit you have to tell us, and there are no right or wrong answers.

What are some of the things people do to keep healthy?

PROMPT #1: Do your friends ever tell you about things they do to stay healthy? Can you tell me what those things are?

PROMPT #2: One of the things someone might do to keep well is to pay attention to her body. What are some other things people do to keep healthy?

What are some of the things YOU do to keep healthy?

PROMPT #1: Do you ever tell your friends good things to do or give them advice about how to stay healthy?

PROMPT #2: Some people eat well to keep healthy. That would be a good example of something you might do to keep healthy. What are some other things you do to keep healthy?

I'm going to ask you some more questions about health care when people are sick. These questions are only about when people are not well.

Please tell me some reasons why a woman would not or could not go to a medical doctor if she were sick.

PROMPT #1: What are some of the things that make it too hard for a woman to get medical care if she were sick?

PROMPT #2: Some women say they have trouble getting their friend or mothers to go to the doctor when she is sick. Has this ever happened to you? What were some of the reasons they gave you?

What are some of the things that might make it too hard for a woman to get medical care if she were sick?

PROMPT #1: If any of your friends or family ever told you reasons they didn't or couldn't get medical care when they were sick, what were those reasons?

PROMPT #2: Some women say that they would go to the doctor if it weren't so hard. Have you ever heard that from your mother or friends? What are some things that might make it hard for them to get to the doctor?

Please tell me some things that would make someone have to put off or delay going to a health professional if she were sick.

PROMPT #1: If any of your friends or family ever told you they would go to the doctor "later," what were the reasons they may have had for saying that?

PROMPT #2: Some women say that they put off going to the doctor because they don't like to go. What are some other reasons someone might put off going to the doctor?

Now I am going to ask you a group of questions about health care when people are healthy. These are only questions about when people are NOT sick.

Please tell me some reasons why a woman would not or could not go to a medical doctor as a part of keeping healthy.

PROMPT #1: What are some of the things that might make it too hard for a woman to get medical care as a part of keeping healthy?

PROMPT #2: Some women say they have trouble getting their friend or mothers to go to the doctor as a part of keeping healthy. Has this ever happened to you? What were some of the reasons they gave you?

What are some of the things that might make it too hard for a woman to get medical care as a part of keeping healthy?

PROMPT #1: If any of your friends or family ever told you reasons they couldn't or didn't get medical care as a part of keeping healthy, what were those reasons?

PROMPT #2: Some women say that they would go to the doctor if it weren't so hard. Have you ever heard that from your mother or friends? What are some things that might make it hard for them to get to the doctor?

Please tell me some things that would make someone have to put off or delay going to a health professional as part of keeping healthy.

PROMPT #1: If any of your friends or family ever told you they would go to the doctor "later," what were the reasons they may have had for saying that?

PROMPT #2: Some women say that they put off going to the doctor because they don't like to go. What are some other reasons someone might put off going to the doctor?

The next set of questions are about mammograms. A mammogram is an x-ray that is taken of the breast that shows any problems.

Please tell me some reasons why a woman could *not* or would *not* get a mammogram.

PROMPT #1: If any of your friends or family ever told you that they couldn't get a mammogram or would never get another again, what were their reasons?

PROMPT #2: What are some of the things that might make it too hard for a woman to get a mammogram?

What are some of the things that might make it too hard for a woman to get a mammogram?

PROMPT #1: If you ever thought it was too hard to get a mammogram, what were your reasons?

Please tell me some things that would make someone have to put off or delay getting a mammogram.

PROMPT #1: If any of your friends or family ever told you they would get a mammogram "later," what were the reasons they may have had for saying that?

PROMPT #2: If you ever said or thought to yourself that you would get a mammogram "later," what were the reasons you had for saying that?

Why do you think a health care professional might tell a woman to have a mammogram?

PROMPT #1: Perhaps a doctor or nurse once told you to have a mammogram. What do you think some of the reasons were that your (type health care professional) said to have a mammogram?

PROMPT #2: What are some of the things a health care professional would want you to have a mammogram for?

Appendix D: Final Semi-Structured Interview Data-Gathering Guide

STAND study – FORM C (For Interviewer)

PIC: _____

Interviewer: _____

Question Set 1:

Can you think of any times when you were sick when you couldn't or didn't get medical care that you wanted?

- What are some of the reasons you didn't get care at that time?
- How did you try to get medical care during that time?
- Did you go to someone else for care after that time?

Can you think of any times when you couldn't or didn't get a check-up or doctor's visit to stay healthy?

- What are some of the reasons you didn't get care at that time?
- How did you try to get medical care during that time?
- Did you go to someone else for care after that time?

Can you think of any time when you couldn't or didn't get a breast exam or mammogram?

- What are some of the reasons you didn't get care at that time?
- How did you try to get medical care during that time?
- Did you go to someone else for care after that time?

How have these experiences affected the way you get medical care now?

Question Set 2

Tell me what you think about going to the medical doctor

Prompt #1: If you had to describe going to a medical doctor to an adult who had never been to a doctor, what would you tell them?

Probe 1: Tell me what a visit to the doctor is like

- What's it like to get an appointment?
- What's it like to get to the appointment?
- What's waiting in the waiting room like?
- What's talking with the staff like?
- What's the examination room like?
- What's talking with the doctor like?
- What's the examination like?
- What's talking to the doctor after the examination like?
- Do you see the same doctor every time you go to the doctor?
- Do you prefer to see the same doctor every time you go? Why?

Have any of these things ever kept you from getting medical care when you are sick?

Have any of these things ever kept you from getting medical care as a part of staying healthy?

Do you think that any of these things might keep you from getting medical care in the future when you are sick?

Do you think that any of these things might keep you from getting care in the future as a part of staying healthy?

Do you think that the sex of the doctor matters?

Probe #1: Tell me what a visit with a female doctor is like?

Probe #2: Tell me what a visit with a male doctor is like?

Do you think that the race of the doctor matters?

Probe #1: Tell me what a visit with an African-American doctor is like?

Probe #2: Tell me what a visit with doctors of other races is like?

- African-Caribbean
- Asian
- Person from India (Asian Indian)
- Latino
- White/Caucasian

Question Set 3:

A mammogram is an x-ray taken only of the breasts by a machine that presses against each breast while a picture is taken.

Tell me what you think about mammograms.

Prompt #1: If you had to describe getting a mammogram to a person who had never heard of them, what would you tell them?

- Probe 1: What do you think you might have to do to make an appointment?
- Probe 2: What do you think you might have to do to get there?
- Probe 3: Tell me what you think a visit might be like.
 - What might a place where you got a mammogram be like?
 - What would talking with the staff be like?
- Probe 4: Tell me what the mammogram might be like.
- Probe 5: Tell me what the technician might be like.
- Probe 6: Tell me what waiting for your result might be like.
- Probe 7: Tell me what getting your result might be like.

Have any of these things ever kept you from getting mammograms in the past?

Do you think that any of these things might keep you from getting mammograms in the future?

Are there other things that might keep you from getting mammograms in the future?

Question Set 4: Explanatory Models:

Think of someone you know who has had breast cancer, or of anyone you've ever heard of or seen on T.V. How did she think she got it?

PROMPT #1: Are there things that people have told you or that you have heard about that can cause breast cancer?

PROMPT #2: Are there things that you worry about doing or getting done to you in case they could cause breast cancer?

How did she think that the cancer could get worse?

PROMPT #1: Are there things that people have told you or that you have heard about that can cause breast cancer to spread or get worse?

PROMPT #2: Are there things that she worried about doing or getting done to her in case they could make breast cancer spread or get worse?

How would you know if you had breast cancer?

PROMPT #1: What might be some signs that a woman has breast cancer?

PROMPT #2: Have you ever noticed something about your breasts that you worry could be breast cancer?

In your opinion, what would treatment for breast cancer be like?

PROMPT #1: If someone you know has had breast cancer, what was the treatment for her cancer like?

PROMPT #2: Have you ever thought about what breast cancer treatment might be like?

- Tell me what you think visits to the Dr. for breast cancer treatment would be like.
- How do you think the breast cancer would be treated?
- What would the experience of getting the cancer treatments be like?
- If you someone you know has had breast cancer, how have her experiences affected the way you think about breast cancer?
- Would these things keep you from getting mammograms or going to the doctor?

Question Set 5: Preventive Care and Genetic Testing Opinions

What are some things people might eat, drink or take to stay healthy?

What is your opinion about taking medicines to keep from getting a specific disease before you are sick?

Please tell me some reasons women might want to take medicines to keep from getting a specific disease before she is sick?

Please tell me some reasons women might not want to take medicines to keep from getting a specific disease before she is sick?

Do you take any medicines to keep from getting sick, what are they, why do you take them?

Who do you talk to in order to make up your mind about taking them?

Who would give you good advice about medicines that keep you from getting sick?

What are some of the things you would do to keep from getting breast cancer?

Have you ever heard of Tamoxifen? Some women are at higher risk for developing breast cancer than other women are. Tamoxifen is a drug that can help prevent breast cancer for women who are at high risk. Usually women take it between two and five years.

Please tell me some reasons a woman might want to take Tamoxifen.

Please tell me some reasons a woman might not want to take Tamoxifen.

Why might you consider taking tamoxifen?

Who would you talk to in order to make up your mind about taking Tamoxifen?

Who would give you good advice about whether or not to take Tamoxifen?

What would make you want to take Tamoxifen?

What would make you not want to take Tamoxifen?

**Sometimes people's genes can affect whether or not they are at high risk for getting a disease.
There are now tests that can show if a woman who has a lot of breast cancer in her family
inherited a gene that makes it more likely that she will also get breast cancer.**

What is your opinion about genetic testing?

Probe 1: What do you think waiting for your result would be like?

Probe 2: What would you use your genetic testing result for?

Probe 3: What would your doctor use your genetic testing result for?

Probe 4: Who would give you good advice about whether or not to get genetic testing?

Probe 5: What might make you want to get genetic testing?

Probe 6: What might make you not want to get genetic testing?

Field Note Writing Guide

These are a few issues that you should address in your field notes both during and as soon as possible after ending the interview. Please write about these and other issues in your notepad as legibly as possible, and submit your notes to the project manager with all other data.

Setting

- Time of Interview
- Location of Interview
- Setting Description

Informant Comfort level

- With interviewer
- With location
- With interview questions

Information shared with Interviewer external to interview

- Employment
- Socioeconomic status
- Personal feelings
- Information about family
- Support relationships
- Personal or family history of breast cancer
- Worries about breasts/breast cancer
- Views about mammograms/breast cancer
- Views about doctors, medical professionals

Impressions about informant

- Behavior patterns
- Speech patterns
- Attitude toward interviewer, interview process

Methods Notes on the interview

- Things that went well
- Things that didn't go well
- Things to improve (methods, interview style, data gathering guides, demographic survey, etc.)

Analytical Notes on the interview

- Phrases informant used
- Metaphors informant used
- Symbols informant used
- Social issues that seem to influence responses (example: informant hints that there is information she is not sharing due to age, race, status as single vs. married.)

Interviewer impressions (critical self appraisal)

- Interviewer feelings going into and throughout interview
- Self appraisal of interview technique
- Response to challenges or encouragement by informant
- Points of possible interaction bias

Other

Any information the interviewer sees as pertinent to the analysis of the interview, understanding the context of the interview, judging whether the interview is to be included in or disincluded from analysis, and improving the project, interview process or personal interview style which is not covered in any of the above categories.

Appendix E: Referral Tree Management Protocol

Referral Tree (Snowball Sampling) Protocol

1. ***Finding respondents and starting referral chains:*** In order to reach as many sectors of the population as possible, we used several different points of contact to start several chains. First, we contacted women who participated in the focus groups and agreed to act as informal research assistants (according to the steps outlined below in step 3). One woman did not have a telephone or a permanent residence but stayed in touch with us via a community representative who works at University of Pennsylvania Ralston House. This woman started a chain of homeless women from a shelter who do not get medical care. One woman normally eschews medical care, and started a chain of women who choose not to go to the doctor. One woman works with several local charity and activist groups. Although she did not start a chain, she referred us to other community leaders who did help us start chains. Additionally, we contacted several breast cancer, social and health organizations, such as the Susan Komen Breast Cancer Foundation, the Linda Creed Breast Cancer Foundation, the Breast Health Institute, Philadelphia Fight, Temple University's Asian Health Project, the Philadelphia Health Initiative, and Congresso Des Latinos. These groups were instrumental in starting chains among the Asian, Latina, Lesbian/Bi, African-American, and traditionally underserved groups, as well as helping us locate women who were underserved for reasons outside the current model of medical underservedness.

Moderators and community leaders or the Project Manager served as the administrator for each of these referral chains, tracking referrals, screening potential respondents for eligibility, and referring respondents to the Project Manager for scheduling interviews. While some moderators and community leaders maintain referral tracking to ensure that they did not refer the same individuals to us more than once, these individuals are not responsible for full demographic-based referral tracking. This step is conducted by our research team through the use of referral-tracing trees, discussed in step 4 of this protocol, and are kept onsite at the University of Pennsylvania by the Project Manager. All referral-tracing trees are treated as confidential research documentation and are kept in a password-protected program, on a password-protected computer, in a locked office in a secured and locked building.

Each woman is asked for as many names as possible of women who cannot get mammograms despite needing them, do not get mammograms, might avoid mammograms, do not have telephones or who might have beliefs about cancer or other diseases that would keep them from seeking screening or curative care.

All names of potential respondents are entered into an MS Access tracking database, along with their contact information, referral source code, and preferred modes and times of contact.

2. ***Verifying the eligibility of potential respondents:*** In order to use our time and our respondent's time wisely, we ask that each respondent contact us either via telephone or arrange through the individual who referred her to meet an interviewer in person in order that we may verify each individual's eligibility. We first explain who we are, what the aims of the project are, and reiterate who referred her to us. We then provide a full overview of what questions we will be asking, how long an interview generally takes, and how the research we are conducting can help people who need better medical care.

If the woman indicates that she is interested in continuing the conversation, we will then gain her verbal consent to be screened for eligibility for the study. Screening questions are written on a data-gathering sheet to ensure that the formal research assistant asks the same questions in the same way of all potential respondents. Because several respondents have been illiterate and one was blind, we ask all eligibility screening questions orally. Once these questions are answered, we tell the individual if she is eligible or not. If she is eligible, the project manager schedules her for an interview with an age- and ethnically-appropriate interviewer, if possible. If no interviewers are available at the respondent's desired time for an interviewer, the project manager conducts the interview.

If the respondent does not meet the criteria of the study, she will be thanked for her time, and no more information will be requested of her.

3. ***Engaging respondents as informal research assistants:*** Each woman who meets the selection criteria and agrees to become a part of the sample is recruited as an informal research assistant insofar as she is asked to refer us to other women who meet the selection criteria. Although women (and men) who themselves do not meet the criteria might prove to know others who do, it is important for two reasons to limit their engagement with the study. First, we do not want women who do not meet the criteria to remain in any way in the sample population, in the event that they are selected from that sample in error and we gather data that cannot be used for this study. Second, retaining ineligible study participants makes it difficult to track the effectiveness of each referral tree and clouds the issue of when a tree should be terminated.

Both at the time of interview scheduling, and at the end of her own interview, each potential respondent is told what the selection criteria are for the study, and are asked to provide as many names as possible of other women who meet those criteria. Generally of these referrals, only one or two women will agree to meet with us and only one will consent to participate and provide the names of other women to contact.

4. ***Controlling the types of chains and cases in any chain:*** In order to reduce bias (i.e. any one chain providing too many potential respondents and thus biasing the sample toward the interests of that group, it is necessary to control both the types of chains that emerge from the referral process and the numbers of cases in any chain. Toward this end, we have created referral-tracing trees, which we use to plot the progress of referral chains, maintain a record of referral sources and track what categories of people were referred by whom. This step, although time consuming, has been necessary. We use a family-tree tracing program not only to track the progress and visual "branching" of the chain, but also enter demographic information regarding each individual in the chain, as obtained through the screening interview. This has given us a sense of the value of each branch of the referral chain (relative to whether or not it refers people who are eligible for the study) that informs our decisions about which chains to terminate or when to initiate new chains at which step of the sample construction process, in addition to pertinent information regarding the overall demographics for each chain of individuals. This information may also provide us with valuable information for future research – an existing sample population, an existing chain to gather a larger population if required, and information about what categories of people are most likely to refer other people from similar categories.

5. **Terminating referral chains:** Referral chains are terminated only when they are consistently yielding potential respondents who do not meet eligibility criteria or after a period of time they yield no new informants. Consistent referrals of ineligible individuals are defined by the following criteria:

- At least two ineligible referrals from chain referee (ineligible people include: women under 40, women 40 and over who get annual mammograms, men, children under 21).

Chains are also terminated when:

- If, after 3 months, no referrals from chain initiator despite contact and encouragement from project manager.
- If, after 6 months, no additional referrals from any chain participants despite contact and encouragement from project manager.
- Chain accrues over 30 people from one sample source.

Chains are terminated in the following way:

- Project manager determines that chain is producing no referrals or consistently referring ineligible individuals (2 or more ineligible individuals).
- Project manager contacts chain referee (person who is referring ineligible individuals) and thanks individual for time, mentions problem, reviews eligibility criteria and negotiates with main chain initiator until main chain initiator agrees to refer eligible individuals and demonstrates understanding of criteria for eligibility.
- Chain referee sensitively and respectfully is given the option to continue participation or opt out for her convenience.
- Project manager records time and date of call, result of call, chain referee's decision.
- If chain referee opts in, her referrals are tracked.
- If chain referee consistently refers 2 or more ineligible individuals 3 months after call (allowing time for individuals told about the study prior to project manager's intervention to contact research team) then project manager calls chain referee, thanks her for her time and explains that no additional referrals are required.
- Project manager calls main chain initiator and explains that no additional referrals are required.

Appendix F: Abstract

“Perceptions of Health as a Homeostatic Condition and Barriers to Tamoxifen Use Among Urban African American Women.”

Perceptions of Health as a Homeostatic Condition and Barriers to Tamoxifen Use Among Urban African American Women

E. Micco, L.T. Dean, K. Armstrong

African American women are at lower risk for developing breast cancer than Caucasian women but are at higher risk of dying from it. Targeting chemoprevention, such as tamoxifen, to high-risk African American women could significantly reduce mortality among this group. The success of a prophylactic intervention depends upon high-risk individuals' access and utilization patterns of that intervention. The newness of this therapy presents the unique opportunity to examine and address potential barriers to chemoprevention prior to their becoming entrenched in social structure and policy. Because the nature of such barriers is unknown, we conducted semi-structured qualitative interviews with twenty urban African American women to identify any barriers that may exist and inform the development of a scaled instrument to measure the prevalence of these potential barriers throughout this community. The most commonly cited responses to general and specific questions regarding preventive medication were the belief that prophylaxis represented negative thinking, which could negatively impact health (N=12) and a reluctance to take medication except in response to immediate illness (N=14). Participants expressed reluctance to take medication overall, but were particularly unwilling to take prescription medication. Repeatedly, participants broke down the concept of medicines into two categories: Good Medicine and Bad Medicine. Probing into the meanings of these two concepts revealed that Bad Medicine is conceived of as any prescription drug that gives no discernable relief of present symptoms and build up in the body over time, which the women conceived of as "toxic." 10 of the 20 women surveyed classified tamoxifen as a Bad Medicine. Further probing revealed that these 10 women did not see the need to introduce "toxins" into one's body in response to a possible illness, as taking any drug could cause side effects and upset the body's natural balance. Additionally, 10 of the participants believed that surgery could cause cancer to spread as a result of disrupting the body's natural structure. The concept of health equaling an essential embodied balance seemed to function as a central theme or framework for many of the participants. It is possible that among women who consider health as a homeostatic condition, not only the perceived "toxic" nature of tamoxifen, but the consideration of breast cancer risk prior to diagnosis could prevent the effective utilization of tamoxifen and other breast cancer preventive measures. Over the next six months we will ask participants to rank these factors in order of importance and use these results to develop a scaled instrument to measure how widespread this health concept may be in the urban African-American community, and to what degree it may function as a barrier to chemoprevention utilization.

Appendix G: Grant Abstract

“Cultural Model of Prevention in African American Women”

Cultural Model of Prevention in African-American Women

A. Specific Aims: African-American women are at lower risk of developing breast cancer but at higher risk of dying of it than Caucasian women [1-3]. Use of effective chemoprevention, such as tamoxifen, among high-risk African-American women could significantly reduce breast cancer mortality among this group. However, considerable barriers may exist to African-American women adopting chemoprevention. Current research in other areas of preventive care points to lack of access to medical care, lack of prescription coverage, distrust of the medical establishment and institutionalized racism as possible barriers [4-7]. Although a model that includes these factors would be a compelling one, it may not be complete. It has been shown that cultural models influence adoption of new technology [8, 9]. Building on existing literature about cultural models of disease and treatment among African-American women, we used semi-structured interviews of African-American women who eschew screening mammograms to develop a preliminary model of disease prevention. Our respondents indicated that this model, characterized by the concept of the body as a fragile homeostatic system that is easily disrupted by impure elements such as unnecessary medications, negative thinking and stress, might also play a role in decision making about chemoprevention.

In order to understand the factors that may impact the uptake and use of chemoprevention among African-American women, the goals of this project are to:

- Verify the elements of the above model, identify any contributing elements our prior research did not uncover, and clarify the dynamic relationships among the elements, resulting in the definition of a culturally specific model of disease prevention among African-American women;
- Determine how the expression of this model varies among African-American women, reflecting and providing further insight into cultural variability within this racially defined group;
- Discover whether this model may affect preventive medical decision making about tamoxifen uptake and use among African-American women who are eligible for tamoxifen therapy; and
- Lay the groundwork for future research examining how the role this model plays among other models known to be important to preventive medical decision making.

We understand that these three goals are complex in nature and that inquiry may provide unanticipated findings. Approaching these aims as a two-step study makes it possible to reduce complexity by compartmentalizing the steps of inquiry, and allow emerging insights to guide inquiry throughout the research process.

Study 1 will guide the accurate representation of the postulated model and inform development of the data gathering guide and cultural consensus model to be used in Study 2. We will triangulate data from existing literature, focus groups and in depth interviews to inform this step.

Study 2 will explore what role the model defined in Study 1 plays in decision making about chemoprevention use among African-American women at increased risk for breast cancer. We will accrue a purposive sample of 120 African-American women with a first-degree relative diagnosed with breast cancer, conduct semi-structured interviews to understand in the women's own words if this model might play a role in decision making about tamoxifen, conduct consensus analysis to estimate how strongly the overall group knows about and believes in the model, and analyze the data to provide preliminary information regarding points of divergence and convergence between the African-American and biomedical models of disease prevention. This last step will help lay the groundwork for future research into breaking down barriers to intra-cultural communication and establishing mutually respectful doctor-patient partnerships for improving and maintaining health.